

UNIQUELY HUMAN

A Different Way
of Seeing Autism

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WITH TOM FIELDS-MEYER

SOUVENIR
PRESS

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To all individuals with autism and their families,
in the hope that this book will help them gain what they
so deserve: understanding and respect.

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AUTHOR'S NOTE

IN this book I have chosen to employ what is known as person-first language. Instead of referring to “an autistic person” or “an autistic”—which makes autism a person’s defining quality—I generally use phrases such as “person with autism,” “child who has autism,” or “adult on the autism spectrum.” I occasionally also use the term “on the spectrum,” which is widely accepted in the autism community. While these are my preferences, they aren’t ideal from all perspectives. This choice of language can sometimes make for awkward and cumbersome prose, so allow me to apologize in advance for that.

I am also aware that others, in particular some adults with autism, prefer the label “autistic,” feeling that autism is indeed a defining characteristic and is essential to their identity and that person-first language implies that autism is inherently bad. (In the same way, you wouldn’t call someone “a person with maleness” but rather “male” or “a male.”) While I fully understand and respect that opinion, I have chosen otherwise for this book.

I occasionally make reference to Asperger’s syndrome, which for many years was a diagnostic subcategory of Autism Spectrum Disorders in the “bible” of diagnosis, the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* of the American Psychiatric Association. Although Asperger’s syndrome was dropped as a formal diagnosis in its most recent edition (known as the *DSM-5*), the term continues to be used commonly to describe people with average or higher cogni-

tive and language ability paired with challenges in the social realm as well as other challenges common in autism.

In referring to individuals who do not (or do not yet) communicate by speaking, I use the term “nonspeaking” and similar language. Others commonly refer to such people as “nonverbal,” but many such people use words and other symbolic means to communicate through sign language, iPads, and other alternative means.

In most cases, when the text refers in general terms to “children” or “kids” with autism, the observations are also relevant to teenagers and adults. I use the terms “typical,” “typically developing,” and “neurotypical” to refer to people who do not have autism.

The English language poses challenges for all writers since it has no gender-neutral pronouns. I have tried to be sensitive to gender by alternating between male and female. Of course nearly all of the material in this book applies equally to males and females. Readers will note that the majority of people I mention in examples are male. This reflects both the real world and my professional experience. Approximately four out of five people with autism are male. This also helps explain why all four of the subjects in chapter 10, which describes trajectories over many years, are young men. While I have met and worked with many girls and young women with autism, all of the individuals with whom I have maintained contact over two decades or more are male.

The underlying philosophy, values, and practices I share in this book are consistent with and in some cases derived from the SCERTS® Model (2006), an educational and treatment framework developed with my colleagues. The SCERTS Model prioritizes social communication, emotional regulation, and transactional support as the most important domains to focus on with individuals with autism. Schools and school districts across the United States and in more than a dozen countries have implemented SCERTS. A more detailed description of the SCERTS Model appears at the end of this book.

INTRODUCTION

A Different Way of Seeing Autism

NOT long ago I was meeting with a group of educators at an elementary school when things suddenly got personal. I was there in my role as a school district consultant for programs serving children with special needs, and as the meeting was breaking up, the principal asked to see me privately. I figured that he wanted to discuss a staff issue, but the principal—an intense, serious man—closed the door, pulled his chair close to mine, looked me in the eye, and began telling me about his nine-year-old son.

He described a shy, quirky, and solitary youngster who had grown increasingly remote and isolated, spending much of his time playing video games by himself and rarely mingling with other children his age. Then he got to the point: a psychologist had recently diagnosed the boy with Autism Spectrum Disorder. The principal leaned forward, putting his face within inches of mine.

“Barry,” he asked, “should I be scared to death?”

It is the sort of question that has become all too familiar to me. Almost every week I meet parents who are intelligent, capable individuals, often confident and accomplished in other realms. But when these mothers and fathers encounter autism, they become

disoriented. They lose faith in their own instincts. Facing this unexpected and unfamiliar territory, they feel bewildered, frightened, and lost.

A few years earlier, the person asking was a world-renowned musician. He and his wife had invited me to observe their four-year-old daughter. The girl had not been responding well to intensive autism therapy that required sitting for long periods and responding to directions and commands. Her parents wanted a second opinion about the best approach to helping and supporting her. On my first visit to the family's sprawling home, the father gestured for me to follow him into another room.

"Can I show you something?" he asked. He reached behind an upholstered chair and grabbed a paper shopping bag, then stuck his hand inside and pulled out a toy. It was a Bumble Ball, a battery-powered, textured rubber toy with a motor inside to make it vibrate when it was switched on. I could see that it had never been removed from its original packaging.

"I bought this for my daughter last Christmas," he said apprehensively. "Was that a bad thing? I thought she would like it."

I shrugged. "I can't see how it could be bad," I replied.

"Well," he said, "her therapist told me it would make her more autistic."

It made no sense: a brilliantly talented celebrity so paralyzed by the words of a thirty-year-old therapist that he was scared to give his own daughter a toy.

For more than four decades it has been my job to help parents like these, people from all walks of life who are struggling with the realization and reality that their children have autism—and to support the educators and various professionals who work with these children. More and more often I meet parents who have been thrown off balance—who suddenly feel perplexed, sad, and anxious about their children, not knowing what an autism diagnosis means for the future of their child and their family.

Their distress and confusion stem partly from information over-

load. Autism Spectrum Disorder is now among the most commonly diagnosed developmental disabilities; the U.S. Centers for Disease Control estimates that it affects as many as one in fifty school-age children. A flood of professionals and programs has emerged to serve these children: physicians, therapists, schools, afterschool programs. There are karate classes and theater programs for children with autism, sports camps and religious schools and yoga classes. At the same time, charlatans and opportunists with minimal or no experience—and even some with professional credentials—advertise their approaches as “breakthroughs.” Unfortunately autism treatment is a largely unregulated enterprise.

All of this has made life even more challenging for parents. Which professional to trust? Who can explain your child? Which treatment will succeed? Which diet? Which therapy? Which medication? Which school? Which tutor?

Like any parents, these mothers and fathers want what’s best for their children. But, struggling with a developmental disability they don’t understand, they don’t know where to turn.

My job for four decades has been to help them transform their desperation into hope, to replace anxiety with knowledge, to turn self-doubt into confidence and comfort, and to help them see as possible what they thought was impossible. I have worked with thousands of families touched by autism, helping them to reframe their experience of the condition, and in turn build healthier, fuller lives. That’s what I hope this book will help you to do, whether you are a parent, a relative, a friend, or a professional working to support these children and their families.

It starts with shifting the way we understand autism. Again and again I have witnessed the same phenomenon: parents come to perceive their child as so radically different from others that the child’s behavior seems beyond comprehension. They have come to believe that the tools and instincts they would bring to raising any other child just won’t work with a child who has autism. Influenced by some professionals, they see certain behaviors as “autistic” and un-

desirable and perceive their goal as eliminating these behaviors and somehow fixing the child.

I have come to believe that this is a flawed understanding—and the wrong approach. Here is my central message: The behavior of people with autism isn't random, deviant, or bizarre, as many professionals have called it for decades. These children don't come from Mars. The things they say aren't—as many professionals still maintain—meaningless or “nonfunctional.”

Autism isn't an illness. It's a different way of being human. Children with autism aren't sick; they are progressing through developmental stages as we all do.* To help them, we don't need to change them or fix them. We need to work to understand them, and then change what *we* do.

In other words, the best way to help a person with autism change for the better is to change ourselves—our attitudes, our behavior, and the types of support we provide.

How to do that? First, by listening. I have worked at the highest levels of academia and served on the faculty of an Ivy League medical school. I have published my work in dozens of scholarly journals and books. I have addressed conferences and presented workshops in nearly every state and across the globe, from China to Israel, from New Zealand to Spain. Yet my most valuable lessons about autism have come not from lectures or journals. They have come from children, their parents, and a handful of extremely articulate adults with the rare ability to explain their own experience of having autism.

One of those is Ros Blackburn, a British woman who speaks more insightfully than practically anyone I know about what it feels like to go through life with autism. Ros often repeats this mantra: “If I do something you don't understand, you've got to keep asking, ‘Why, why, *why?*’”

*While many children with autism experience co-occurring medical issues—including gastrointestinal and sleep disorders, allergies, and ear infections—most are free of these challenges, which are not definitive of autism.

This book is about what I have learned in forty years of asking why—what I have come to understand by asking what it feels like to have autism.

Concerned parents share the same kinds of questions: Why does he rock his body? Why won't he stop talking about trains? Why does she repeat lines from movies over and over? Why does he obsessively adjust the miniblinds? Why is he terrified of butterflies? Why does she stare at the ceiling fan?

Some professionals simply categorize these as “autistic behaviors.” Too often the ultimate goal of professionals and parents is to reduce or eliminate these behaviors—to stop the spinning, stop the arm flapping, stop the repeating—without asking, “Why?”

Here is what I have learned from my years in the field and from Ros Blackburn and others: There is no such thing as autistic behavior. These are all *human* behaviors and *human* responses based on a person's experience.

When I present workshops and seminars about autism, I often tell the audience that I have never seen a person with autism do something that I haven't seen a so-called normal person do. Of course, many people find this difficult to believe. So I make it a challenge. I ask the listeners—usually parents, teachers, and professionals—to name a behavior that is central to autism, and I predict that I have witnessed it in a typical person. Immediately people in the audience raise their hands.

“How about repeating the same phrase over and over one thousand times?”

Plenty of kids do that when they're asking for an ice cream cone or how much longer the drive will be.

“Talking to yourself when nobody's around?”

I do that in my car every day.

“Banging her head on the ground when she's frustrated?”

My neighbor's “typical” son did that when he was a toddler.

Rocking, talking to yourself, jumping up and down, flapping your arms? We all do these things. The difference, of course, is that you

might not have seen it as persistently or as intensely (or at an older age) in a typical person. And if we do engage in such behavior, we generally make sure we're not doing so in public.

Ros Blackburn says people stare when she jumps up and down and flaps her arms. They're simply not accustomed to seeing an adult act with such abandon. She points out that it's common to see people on TV doing just what she does, after they've won the lottery or a game show. "The difference," she says, "is that I get excited more easily than you do."

We're all human, and these are human behaviors.

That's the paradigm shift this book will bring: instead of classifying legitimate, functional behavior as a sign of pathology, we'll examine it as part of a range of strategies to cope, to adapt, to communicate and deal with a world that feels overwhelming and frightening. Some of the most popular autism therapies make it their sole aim to reduce or *eliminate* behaviors. I'll show how it's better to enhance abilities, teach skills, build coping strategies, and offer supports that will help to prevent behavioral patterns of concern and naturally lead to more desirable behavior.

It's not helpful to dismiss what children do as "autistic behavior" or "aberrant behavior" or "noncompliant behavior" (a phrase used by many therapists). Instead of dismissing it, it's better to ask: What is motivating it? What purpose does it serve? Does it actually help the person, even though it looks different?

I don't have simple answers, but I can offer ways that will lead to a better understanding of children, teens, and adults with autism. The stories in *Uniquely Human* span my four-decade career in many different settings and roles: my early work in summer camp programs, positions at university and hospital clinics, and seventeen years in private practice. They also describe my experiences consulting for more than one hundred public school districts, for hospitals, private agencies, and families, and from many years of traveling the world leading training workshops and consulting. The weekend parent retreat I have facilitated for two decades has given me the opportunity

to learn from parents and develop many deep and enduring friendships. Finally, through many conferences and workshops, I have met and presented with leaders of the autism self-advocacy movement, many of whom have become valued friends.

This book offers a comprehensive approach based on my research and work with colleagues, my experience with families and professionals, and the insights shared by people on the spectrum from whom I have learned much.

It's the book I wish I had been able to read more than four decades ago, when I first lived with and cared for people with autism. Many professionals enter the autism field because of a personal connection—a child or a relative with autism. I happened into it almost by accident. After my first year of college, I landed an unfulfilling summer job in a New York City print shop. My girlfriend was teaching music at a sleep-away camp for children and adults with disabilities. A couple of weeks into the summer, she phoned to tell me there was an opening for a counselor. I applied, got the job, and literally overnight found myself, at just eighteen, responsible for a cabin full of boys with a variety of developmental disabilities.

For a boy from Brooklyn, the isolated rural setting in upstate New York felt like a primitive wilderness. But I was even more unprepared for the people I met. One eight-year-old boy in my cabin seemed remote and disconnected, but he had a knack for repeating phrases or whole sentences he heard. Another camper, a young adult known affectionately as Uncle Eddie, lumbered and spoke as if in slow motion because of his seizure medication. He had the endearing habit of offering compliments without inhibition. "Hi Barry," he'd say. "You look *sooo* handsome todaaay."

I felt like I was entering a different culture with different rules of relating and being, full of people who acted very differently from anyone I had met. Yet I soon became so comfortable and so thoroughly enjoyed my campers that I wanted to understand more. In particular, why did these people struggle so much with communicating their thoughts and feelings, and how could we help them? That

initial experience inspired me to study developmental psycholinguistics, and then speech and language pathology and child development, and eventually to go on to earn a doctorate in communication disorders and sciences.

This book might have also helped me understand one of my closest friends from my childhood in Brooklyn in the 1960s. Lenny was a brilliant student—skipping two grades before high school—and a talented self-taught guitarist. He was a musical genius, stealing guitar licks from Eric Clapton and Jimi Hendrix before the rest of us had even heard of them.

He was one of the most interesting people I knew, and also one of the most anxious, unfiltered, direct, and abrasive. Peers were put off by his frequent comments about his own superior intelligence. When Lenny lived in his own apartment as an adult, his shelves were lined with his extensive collection of records and first-edition comic books, all in plastic sleeves, impeccably organized and catalogued. But his kitchen sink was routinely overflowing with dirty dishes, his clothes strewn everywhere. Lenny had perfect SAT scores, eventually earned two master's degrees and a law degree, but had a difficult time keeping a job because he had trouble getting along with people.

Still, if Lenny knew you well and trusted you, and if you had common interests, he was as loyal and caring a friend as I have known. Though I frequently found myself in the position of explaining Lenny's eccentric ways to acquaintances—most people thought him rude and arrogant—it took decades before it dawned on me that he probably had Asperger's syndrome. (Asperger's wasn't a formal diagnosis in the United States until 1994.) When Lenny died in his sixties, it struck me that his life surely would have been easier if those around him had better understood what was causing his unusual habits and often brusque manner.

Finally, this is the book I wish I had been able to share a few decades ago with the parents of Michael, one of the first little boys with autism whose family I came to know well. I was a newly minted

PhD, teaching at a large university in the Midwest, and Michael was the nine-year-old son of an English professor. Like many children with autism, Michael had a habit of fluttering his fingers in front of his eyes and staring at them, apparently delighted and captivated. For long stretches he would sit, mesmerized by the movement of his own hands. His teachers and parents routinely badgered Michael to dissuade him: “Michael, put your hands down. . . . Michael, stop looking at your hands!” But he persisted, eventually learning to enjoy secretively peeking at his hands during routine activities such as playing piano.

Around that time Michael’s grandfather died. Michael had developed a very close relationship to his grandfather, spending time with him every weekend, and the death was his first experience of loss. Of course he felt confused and anxious, repeatedly asking his parents when he would be able to see his grandfather again. They explained that Grandpa was in heaven and that some day, in the very distant future, Michael would surely join him there. Michael listened intently, then replied with a single question: “In heaven, are people allowed to look at their hands?”

When Michael considered the idea of eternal bliss, that was what came to mind: not angels and harps and eternal sunshine, but a world where he could watch his own fingers flutter when he wanted to.

His simple question taught me much about Michael and about autism. I have seen hundreds of children with autism who visually fixate on something: their fingers, a toy they carry with them, a fan, garden sprinklers. You could call that “autistic” behavior, or you could watch, listen, pay attention, and ask why they do it. When I have done that I have learned what underlies a fixation like Michael’s: he finds it calming and grounding; it provides a sense of predictability; it’s within his control. With that understanding and insight, behavior like Michael’s isn’t so strange—it’s a unique way of being human.

This book’s scope encompasses the full spectrum of autism, including the most extreme challenges facing individuals of all ages

and their families. I am well aware of how debilitating and stressful some patterns of behavior can be. I have cared for individuals who are so overwhelmed by pain or confusion that their behavior becomes dangerous, destructive, and even harmful to themselves and others. I have directly experienced injuries (bites, bruises, scratches, broken fingers) while attempting to support people in extreme states of distress. I have lived with people with autism who also have sleep disorders, and I have experienced the frustration of trying to ensure proper nutrition for individuals with highly restricted food preferences. I have dealt with children who have become lost, have fled, or have unintentionally put themselves and others in danger.

While I don't claim to have experienced the chronic level of stress and concern that a parent might, I know those concerns and fears intimately. From observing and supporting countless families, I have learned this important lesson: Even under extremely challenging circumstances, our attitudes about and perspective on people with autism and their behavior make a critical difference in their lives—and in ours.

That is the message I hope to share in this book—one that can eliminate the fear I sensed from the principal and the musician and replace it with awe and love. It's the heart of what I taught recently at an autism workshop in Nanaimo, a small city in British Columbia. Throughout the two days there a young father in a baseball cap sat in the front row with his wife, taking it all in but not speaking. The moment the workshop ended, he rushed up to me, hugged me, and buried his head in my shoulder.

"You have opened my eyes," he said, "and I will always be grateful."

I hope this book will open your eyes—and your ears and your heart. I hope to capture and share the unique spirit of the many children, adolescents, and adults with autism I have known—their enthusiasm, their sense of wonder, their honesty and innocence. I will also describe the many obstacles I have seen these individuals and their families overcome. In turn, I hope you will be able to learn

from what I have learned. Despite the challenges you may experience as a parent, family member, educator, or one of the many people who help individuals on the spectrum, my hope is that understanding what it means to be uniquely human will make your experience with these distinctive people deeper, more awe-inspiring, and more joyful.